

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

October 26, 1998

Monolingual Hispanic, Lower education

Miami, Florida

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SECTION 1: GENERAL IMMUNIZATIONS AND HEALTHCARE

I. Prevention

Diseases mentioned:

- Hepatitis
- Tuberculosis
- Polio
- Gastrointestinal disease
- Ear diseases (infections)

II. Immunization

A. *Reasons not to get vaccinated*

- Lack of information
- Fear side effects
- Religion
- Lack of financial resources
- Distrusting the effect of the immunization

B. *Reasons to get vaccinated*

- To avoid getting ill
- To avoid possible suffering
- To ensure a good future for their children
- To raise healthy children

C. *Ways parents are reminded of vaccine schedule*

- Personal record card given to new parents
- Reminder calls or letters from doctors and/or clinics
- Reminders from schools
- Information on radio and television (Respondents thought that increased notices on radio and television would serve to remind and inform parents about immunizations.)

SECTION 2: IMMUNIZATION REGISTRIES

I. Initial reactions to the idea of a registry

Positive reactions:

- The registry would be useful for people moving to another location.
- The registry will provide quick information for schools.
- It will assist in monitoring immunizations.
- Information will be readily available in case of emergency.

Negative reactions/concerns:

- Information will not be recorded in the registry in a timely and correct manner.
- Accessing information might be very bureaucratic and difficult.

Other concerns:

- Will the registry be trustworthy?
- How does one obtain information from the registry?
- Who will have access?
- Will the registry be operated by private citizens or by the government?
- Will there be any cost to the public for operating and/or accessing the registry?
- Will the people operating the registry and recording information be trained to handle their jobs efficiently and professionally?

II. Content of the registries

A. Initial reactions to the type of information typically in a registry

- Overall, respondents said they would be comfortable with the inclusion of the following information:
 - Date of the vaccination
 - Manufacturer of the vaccine
 - Vaccine lot number
 - Type of vaccine
 - Child's Social Security number (to avoid any confusion)

B. Reactions to including home address and phone number

- Respondents expressed no opposition to including this information.

C. Reactions to including parent or child Social Security number

- Most respondents felt this information would eliminate confusion among children who have the same names.
- Many respondents felt that having the SSN on file would be helpful in case of emergency.
- Only a few respondents were negative about the inclusion of Social Security numbers. They felt these numbers should not be public information. They also felt that inclusion might make this information accessible to people who would falsify records or use the numbers themselves.

D. Reactions to including healthcare members enrollment (WIC, Medicaid numbers)

- Respondents were positive about including Medicaid and WIC numbers as similar information is already noted there.
- They welcomed the concept of these agencies' communications with other health agencies.

III. Access

A. Who should have access

- Parents/Legal guardians
- Doctors
- School, day care and nursery administrators (in case of emergency only)
- Child care centers
- Medical researchers

B. Who should not have access

- Health insurance companies (which should have parental authorization to obtain information)
- Neighbors, in-laws, and other extended family members

IV. Consent and Inclusion

A. Reactions to “opting out” option

- Respondents indicated that this option protected the greatest number of children.
- They felt this option would include more children and that children would not be excluded due to parental neglect.
- Some respondents said they were concerned that information would be included without their consent.

- All respondents indicated that, if they lived in a state with this policy, none would use this option.

B. Reactions to “consent” option

- Most respondents did not like this option. They said it would exclude children whose parents forgot to respond due to fear, neglect, or forgetfulness.
- These participants indicated that, if they lived in a state with this policy, they would consent to have their child registered.

C. Reactions to “automatic” option

- Some respondents liked this option because it requires that information be included in the registry.
- They felt this option would eliminate the risk that a child might be excluded and that it protected the child.
- Respondents felt the disadvantage of this option was the lack of freedom of choice. However, they said that was a small inconvenience compared to the protection of their children.

SECTION 3: WRAP UP AND CLOSING

I. Most important benefit(s) of registries

- Fast, easy access for medical professionals
- Convenience
- Reduced possibility of receiving the same vaccine twice
- Faster access to information in case of emergency
- Better coordination with other programs such as Medicaid
- Accurate records about adverse reactions to vaccinations and other medications

II. Greatest concern(s)/biggest risk(s)

- Failure of technology (e.g., computer not functioning)
- Incorrect information entered in the registry
- Breaches of confidentiality

III. Influence of healthcare provider in decision to participate in a registry

- Respondents felt that they, as parents, would be the primary decision-maker. Their doctors' recommendations would not weigh heavily on their decision to participate in a registry.

IV. Suggestions/comments to people who are responsible for how system works

The registry should be mandatory to all. They should take care to ensure the privacy of the information.

The registry is an excellent idea. Its future would bring good things to our children.

Provide information to the parents about the advantages of the registry so it would have higher acceptance in the community.

The information should not be public information. Only the appropriate medical agencies should have access to the information.

Hire capable and professional personnel to ensure the appropriate handling of information. An error in information could be fatal to a child.

Make the registry available as soon as possible. Make it available to all children in Miami.

Make sure that the information will be held in confidence and not available to the public at large.

Thank you for your concern for our children's health.